



Medicare Rights Center

**Testimony of
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**United States House of Representatives Committee on Government Reform
Subcommittee on Regulatory Affairs**

**"Another Year Another Billion Hours:
Evaluating Paperwork Reduction Efforts in the Federal Government."
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Chairwoman Miller, Mr. Lynch, members of the House Subcommittee on Regulatory Affairs: we at the Medicare Rights Center work each day with older and disabled Americans to assist them in navigating the nation's health care system. This year much of our work has focused on helping men and women – especially the frailest and poorest people with Medicare – navigate the terribly complex Part D prescription drug program. We appreciate this opportunity to share with the Committee how the design of this needlessly complex federal program causes far worse consequences than wasteful paperwork, although that it does. Paperwork reduction in the form of streamlined and straight-forward health assistance programs, do more than save money. They save lives.

Medicare Part D is a clear example of a disastrous partnership of public and private bureaucracies coming together to deny tens of millions of Americans the health care they need.

The Medicare Rights Center (MRC) is the largest independent source of Medicare information and assistance in the United States. Founded in 1989, MRC helps older adults and people with disabilities obtain good affordable health care. Every day we assist people with Medicare as they navigate the health care system, enroll in programs that can help them pay for health care, and overcome barriers to needed care.

The Medicare Rights Center is a not-for-profit consumer service organization, with staff in New York, Washington, Chicago and Baltimore. It is supported by foundation grants, individual donations and contracts with both the public and private sectors. We are consumer driven and independent, relying on a small staff and hundreds of deeply committed volunteers to carry out our mission. We are not supported by the pharmaceutical industry, insurance companies or any other special interest group. Our non-partisan mission is to serve the 43 million men and women with Medicare.

Through national and state telephone hotlines, casework and professional and public education programs, MRC provides direct assistance to people with Medicare from coast to coast. Each year, the Medicare Rights Center receives nearly 100,000 calls for assistance from people with Medicare. Our counselors are trained to assist consumers with complex problems and we complement the basic services offered by the 1-800-MEDICARE hotline operated by the Centers for Medicare and Medicaid Services (CMS). Over the years, 800-MEDICARE has been the largest source of referrals to our hotline; MRC receives no CMS support for its consumer hotline.

MRC also brings to professional counselors, care givers and consumers across the country *Medicare Interactive*, a web-based counseling tool—developed with major foundation support and with a seed technology grant from the United States Department of Commerce. *Medicare Interactive* assists people with Medicare access benefits, including Part D.

This year we have launched a Part D appeals program, recruiting a battery of volunteer lawyers and physicians to assist people with Medicare obtain medications denied to them by their Part D plans. Drug plans place the Medicare Rights Center's toll free phone number on notices informing their enrollees that the Part D plan is denying coverage of a prescribed medication. Since we receive no federal or state financial support to assist people with these Part D appeals, we can only make a dent in the great need for this assistance. It is an extremely complex program, requiring multiple administrative steps and imposing standards and paperwork that varies among the hundreds of drug plans. As a consequence of this complexity and inconsistency, the Part D appeals and exceptions process is, for most people with Medicare, a sham if they do not have competent, independent representation.

We also reach out into low-income communities and have concentrated our services on enrolling people with Medicare in low-income programs. Indeed, one of MRC's key priorities is to enroll as many people as possible in the Low Income Subsidy (LIS) of the Medicare drug benefit, a program commonly known as Extra Help. With foundation support, we have enlisted hundreds of volunteers to reach out to likely candidates for Extra Help, explain the program to them and whenever possible enroll them online through the Social Security web site. These efforts make us particularly well-versed in the issues being discussed at today's hearing – the Extra Help program under Part D, is one of the clearest example of the human deprivation caused by unnecessary government bureaucracy.

Those of you who were members of Congress in 2003 know from personal experience that the Medicare Modernization Act (MMA) that enacted the Part D drug benefit rejected the consumer-friendly model of Medicare that has served older and disabled Americans so well for over 40 years. Rather than create a *Medicare* drug benefit, that Congress appropriated massive subsidies to launch a new cottage industry of for-profit insurers selling what proved to be incomprehensible benefit packages to many of the 43 million Americans with Medicare. Those subsidies spawned an exploitative Wild West marketplace: 1,400 drug plans – most with varying deductibles, co-insurance, co-payments, pharmacy networks and covered drugs – went to work marketing their wares to a largely unprepared consumer base of older and disabled men and women. As this Committee understands better than most, complex is bad and very complex is very bad. I cannot identify a more complex public benefit program ever enacted by the U.S. Congress than the Part D prescription drug program.

The impact on the consumer is obvious and devastating. Millions of these consumers are the nation's oldest, frailest, sickest and least educated Americans. There is too much material to review, too little ability to absorb it, and almost no opportunity to understand it. And no amount of paperwork will be sufficient for the scores of federal and state agencies that must get involved through regulation to tame this industry, this profiteering and insatiable beast that is part pharmaceutical industry, part insurance industry.

This Committee could spend weeks trying to understand the multiple layers of regulation, paperwork and bureaucratic hurdles that the Part D program has triggered. Millions of our parents and grandparents have been forced to do just that. The estimate by the Office of Management and Budget that it takes 30 minutes to fill out a Part D application is both laughable and irrelevant.

This afternoon, I will underscore the human harm and economic waste caused by two aspects of the Part D program: one, the reality faced by people with Medicare who are confronted with between 40

and 80 drug programs offering incomprehensible benefit packages at varying costs; and two, the bureaucratic demands that prevent the majority of impoverished people with Medicare from securing the promised low-income subsidy that they so desperately need.

Ms. R is a 45-year-old woman from upstate New York. She has Medicare because of a disability. In January, eager to obtain Medicare coverage for her anti-psychotics and anti-depressants, Ms. R called 800-MEDICARE for help finding a prescription drug plan. After providing the customer service representative her prescription drug needs and pharmacy preferences, she was encouraged to enroll in the AARP Medicare Rx plan. However, before she was able to complete her enrollment, the call was disconnected.

Ms. R immediately redialed 800-MEDICARE, this time speaking to a different representative who, after gathering the same information about Ms. R's prescription drug needs and pharmacy preferences, helped her enroll in the PacifiCare Rx Solutions plan. She soon received a membership card from PacifiCare, which she was able to use at the pharmacy until mid-April when PacifiCare cancelled her enrollment.

Alarmed, with half a month's supply of drugs left, Ms. R called PacifiCare and was told her enrollment was cancelled because when she signed up she was already enrolled the AARP Medicare Rx plan. She was also told that she would be required to reimburse PacifiCare Rx for the drugs they had already covered.

Meanwhile, Medicare Rx informed her that in order to be reimbursed by them for the drugs PacifiCare had covered she would need to complete their reimbursement forms and submit copies of the original doctors' prescription and pharmacy receipts. But because she had not paid any of the plan's premiums, Medicare Rx informed her that she would soon be disenrolled by its plan.

Ms. R made several attempts to resolve these issues with PacifiCare and Medicare Rx but was met each time with confusing information, conflicting advice and dead-ends. By the time the Medicare Rights Center (MRC) intervened, Ms. R had already gone two weeks without her anti-depressants and anti-psychotics. She was facing a major bout of psychiatric decompensation.

Selecting a Part D Plan

By now, I am sure that you each are familiar with the general parameters of the Part D drug program. We know that Congressional constituent services staffs were as overwhelmed by pleas for help as our hotlines were over the first five months of this year. And I am sure you are aware that it will be starting up all over again in a few months. Nearly everyone expects some Part D plans to leave the market, new ones will enter, and nearly all plans will once again change their benefit packages to add dollars to their bottom lines – after all, each of these commercial drug plan sponsors has a legal obligation to their shareholders to maximize profits.

Bottom line: even the savviest Medicare consumers have been confounded by the complexity of this marketplace and by the inaccurate and conflicting information available to them from both the Administration and the drug plans. Since last fall, people with Medicare have been inundated with marketing materials from drugs plans that are, at best, incomplete and, at worst, purposefully deceptive. Deception comes in many forms: omitting material information from drug plan advertising is one that is epidemic in Part D. For example, information about utilization management techniques (such as requirements that physicians get prior authorization from the plan before it will cover a drug on its

formulary or quantity limits on particular drugs) is often omitted from or hard to locate on plan formularies—resulting in many surprises at the pharmacy counter.

There now are two main sources of information to assist people navigate the drug plans' offerings: the hotline and web site maintained (at great public expense) by the Centers for Medicare and Medicaid Services (CMS) and the separately administered hotlines that the hundreds of for-profit drug plans are required to operate. These are the sources that consumers and counselors helping those consumers must use.

At the request of members of Congress, the General Accountability Office (GAO) evaluated these services to see if people with Medicare were getting real help. The findings from each survey were appalling. Given the structure of this program, it is difficult to blame the human beings charged with administering it. But that is of no comfort to people with Medicare who look to this program, literally in many cases, for life-sustaining help.

When talking to the hotlines run by the for profit drug plans, the GAO obtained accurate and complete responses to one-third of their questions (15% of their questions went unanswered and 51% were either inaccurate or incomplete). That .334 success rate would be good for a baseball player, but disgraceful when you are being paid by the American taxpayers to provide a basic need to older Americans desperately trying to make the right decision because your heart pills or your chemotherapy or your diabetes medicine depends on it.

CMS's 800-MEDICARE hotline fared better, answering GAO questions accurately and completely two-thirds of the time (5% of questions were not answered and 26% were inaccurate, incomplete, or inappropriate).

Aside from these dysfunctional phone help lines, CMS has spent tens of millions of dollars developing its web site – and for good reason: we agree that the only chance a consumer has to make a competent selection of Part D plans is with the help of the most sophisticated web technology. But the web site, again reflecting the complex and constantly changing nature of the drug plan offerings, is rarely dependable. (GAO also evaluated the Medicare website and tactfully described it as “difficult to use.”) But what is wrong with this picture? The Administration concedes that the web tool is essential to select a plan. Yet, it was common during the critical initial enrollment period to find conflicting information between the CMS drug plan search and the plans' own web sites. In addition, three out of four people with Medicare have never even been on the internet

Problems do not end once a person has sifted through dozens of formularies and benefit structures and enrolls in a plan. Plans are allowed to deny coverage of prescriptions and patients are allowed to make a showing of medical necessity to obtain medicines initially denied by the plan. (Of course, denials of coverage for drug plans – as for any insurer – inflate the profit margin for the plan sponsor.) As already noted, the Part D appeals process is impossible for the average person to navigate. Many Medicare Rights Center clients report that they cannot even obtain the proper form or correct information about a plan's appeals process from the plan. Irrationally, there is no standardized appeals process. There should be one form and one set of rules for obtaining an exception. Obtaining life-saving medications should not require navigating a mine-field.

Mrs. S is 92-years old and lives in Carmel, NY. Because she has both Medicare and Medicaid she was randomly enrolled by CMS in the GHI Medicare prescription drug plan, which her daughter discovered did not cover several of her drugs. After spending two days researching other plans (using both the Medicare website and the websites of plan

sponsors), Mrs. S's daughter helped her enroll the AARP Medicare Rx plan, which listed all of her drugs on its formulary.

On January 3, 2006, with one day's worth of medication left, Mrs. S went to the pharmacy to fill her prescriptions. The pharmacist informed her that in order to fill three of her prescriptions, Mrs. S's doctor would need to get prior authorization from her drug plan. Mrs. S's daughter called Medicare Rx but was unsuccessful in obtaining any useful information, such as where to send the request for prior authorization. Neither the plan nor the pharmacy provided any information about the CMS transition policy to provide a temporary supply of non-formulary drugs the first time a person tries to refill a prescription in order to provide enrollees with sufficient time and guidance to work with their health care providers to switch to a therapeutically appropriate formulary alternative, or to request a formulary exception if medically necessary.

On January 5, 2006, the Medicare Rights Center forwarded this case to CMS for assistance in submitting a request for prior authorization and reminding the drug plan of their obligations under the CMS mandated transition policy. As a result, Mrs. S's doctor was able to submit a request for prior authorization, which he marked "urgent."

On January 17, 2006, Mrs. S contacted the Medicare Rights Center (MRC) again because Medicare Rx had not responded to her doctor's request or provided a transition fill of her medications. Fortunately, Mrs. S's doctor was able to provide samples of her medications; however his supply was running low. MRC informed Mrs. S of New York's emergency Medicaid coverage and referred her to the pharmacy again. The pharmacist turned Mrs. S away empty-handed again telling her that Medicaid could no longer be billed for her prescriptions.

The Extra Help Program

There has long been broad, bipartisan agreement that people with Medicare who have very low incomes and resources deserved assistance with the cost of prescription drugs. The low income subsidy (LIS), also known as the Extra Help Program, was devised to allow extremely poor people to participate in the Part D program by reducing their out-of-pocket costs, including premiums, deductibles, co-payments and the infamous "donut hole" – the gap in coverage many people fall into at some point in the year. Like so many other means-tested programs that promise help to America's poor, this promise of help is but an unfulfilled promise to the majority of Americans in need. The reason: bureaucratic disentanglement – the inevitable consequence of indecipherable rules, incomprehensible paperwork and bumbling bureaucracies that resemble Charles Dickens's famous "Department of Circumlocution", which had as its task the duty to make sure that nothing ever happened.

Three out of four Americans who are eligible to sign up for the Extra Help Program—people in dire need of assistance to pay for their medicine—have not signed up. Why? Take a look at the seven page application Medicare's most vulnerable men and women have to complete: it is filled with intimidating questions about bank accounts, life insurance policies, in-kind support and living arrangements. Madame Chairman, can you tell us what the face value of your life insurance policy is? I could not, but to qualify for the Extra Help Program my 94-year old neighbor living in a nursing home has to – signing the application as accurate under pain of fine and/or imprisonment.

I would like to spend a few minutes talking about the experiences of those that do venture forth and succeed in enrolling in the Extra Help Program. With and without the help of our enrollment team, many have found themselves tangled in web of data mismatches, computer system errors and general

bureaucratic messiness. As a result, even now, seven and half months after the start of prescription drug coverage through Medicare, many people are not able to access essential prescription drugs.

Under the current system used by the Social Security Administration (SSA), when a person files an application for the Extra Help Program his personal information is checked against government records, including those of Social Security and the Internal Revenue Service (IRS). If the person's application does not match these records, the application is forwarded to a Social Security field officer who is charged with correcting the mismatch.

Social Security itself keeps two sets of records on individuals. One is the payment record and the other is the actual Social Security card record, called the Numerical Identification File (NUMIDENT) records. Many applicants for the LIS use their Social Security check or statement to obtain information for the LIS application. Applicants often use the social security number, spelling of their name and address as it is printed on these documents, because they assume that the information is correct as listed.

When a person files an application for the LIS his personal information is checked against the Social Security NUMIDENT records. A person's information may not match the information in the SSA NUMIDENT records for multiple reasons. Widows may provide their deceased husbands' Social Security number as that is the number they use for Medicare benefits. Often the error has to do with the spelling of the name on the Social Security check or statement that the applicant relied on. Another common error occurs around the use of middle names and initials that have been left out of the application. Some applicants with names of Asian descent have been denied because SSA listed the order of the name incorrectly, entering the last name as the first, on the Social Security check or statement. Advocates have seen that as many as 1 out of 10 applications have been delayed because an applicant's information did not perfectly match the general Social Security payment records.

It is well known that locating and filing applications for people eligible for the Extra Help Program has proven extremely difficult for SSA and for local community organizations, despite significant efforts. The determination process should not be made more challenging because of unnecessary delays or denials by SSA due to conflicting information in their computer records. The current process should be amended so that all personal information is checked against both the SSA payment records and against the NUMIDENT records prior to having a person's application either returned to the applicant or denied based on incorrect systems information. Having personal information checked against both SSA sources will ensure that otherwise eligible applicants are not unnecessarily being delayed assistance or denied LIS benefits.

When people are denied because of the information in the SSA computer records they either think they are not eligible and therefore miss out on the LIS benefit, or they need to challenge the information in the Social Security records. Without the assistance of a personal representative or advocate, however, many people who are eligible may not know that they should challenge the information as listed in the records. The current system creates more work for SSA because a person may re-submit an application and/or they may work to have their information changed in the Social Security files. It would be far more efficient and expedient to have a system in place from the beginning that verifies information in all the available SSA databases for a correct match, rather than delaying an applicant the valuable LIS benefit based on faulty information in one database.

Further, numerous access problems result because there is no universal way for consumers to prove their Extra Help status. Some plans accept the SSA award letter as proof while others say they have to wait until CMS transfers the information to them electronically. As a result of these kinds of

bureaucratic follies, people are over-charged at the pharmacy counter or inappropriately billed for premiums they cannot afford and should be exempt from.

Mr. M recently turned 65 and became eligible for Medicare. He receives \$750 a month from Social Security and has less than \$20.00 in his checking account. Because Mr. M struggles to make ends meet each month, a friend gives him \$1,000 every four months.

He received a letter from Social Security telling him he may be eligible for Extra Help with his prescription drug costs. Excited Mr. M started to complete the application but counted the full \$1,000 he receives from his friend every four months in his monthly income (rather than dividing it by four). Because he did not divide this amount by four he thought he had too much income to qualify for help.

Deflated, Mr. M called the Medicare Rights Center (MRC) for help. A counselor noticed Mr. M's mistake and helped him submit his Extra Help application online.

Had Mr. M submitted the application to Social Security with the mistake, SSA would have no way of knowing Mr. M had incorrectly applied that amount in his monthly income and would have denied his application.

Mrs. C is 80 years old and lives in Queens. She has Medicare and Medicaid coverage. At her doctor's suggestion, Mrs. C enrolled in a Medicare HMO with Elderplan. Mrs. C did not realize that by joining the Elderplan HMO, she was also joining their drug plan.

In February, Mrs. C went to her local pharmacy to fill her prescription for Fosamax, which treats her osteoporosis. The pharmacist informed Mrs. C that Fosamax was not a preferred brand name drug under Elderplan and she would therefore have to pay a \$50 co-pay to have the prescription filled. Having never paid more than a few dollars for her prescriptions in the past, Mrs. C was flustered and left the pharmacy without filling her prescription.

Mrs. C called the Medicare Rights Center (MRC) for help. A caseworker from MRC called Elderplan and learned that they had no record of Mrs. C's dual eligible status. The MRC caseworker was able to convince Elderplan to put an alert on Mrs. C's account to confirm her dual eligible status with CMS. MRC also forwarded the case to CMS.

A few days later, Mrs. C went returned to her pharmacy and was charged \$5 for her Fosamax—which was still over what she should be paying as a dual eligible.

Bureaucratic Disentitlement Is Not Limited to the New Extra Help Program

While Medicare's new drug benefit helps highlight the issue, bureaucratic disentitlement is nothing new. The Medicare Savings Programs, which help low-income individuals pay their Medicare cost-sharing, have been available for nearly 20 years and still only about one-half of eligible individuals nationwide are actually enrolled. Medicaid, now 40 years old, boasts similarly low enrollment rates.

The reasons for these low participation rates are various complicated and intrusive application procedures. Medicaid applications are invariably daunting: in New York, it is 16-pages long, the font is small, the questions confusing and intrusive and a face-to-face interview is required. Similarly, taxing documentation requirement often deter people from applying at all or result it incomplete and subsequently voided applications, delayed or denied coverage.

Perhaps most frustrating are the stories of those who follow all the rules, jump through all the hoops, and still are turned away—maybe it is a misinformed or overburdened case worker or maybe it is a language barrier or an accessibility issue.

Mr. C lives in Rockland County, NY. He is 64 years old and has Parkinson's disease. When Mr. C called the Medicare Rights Center (MRC) he had already tried several times to submit his Medicare Savings Program application but had been turned away by the Medicaid office each time.

The eligibility requirements of this program are strict. Mr. C needed to locate and produce a hefty stack of documentation to support his application, fill out complicated forms, and subject himself to humiliating questions during a face-to-face interview required by New York State. Nevertheless, Mr. C needed this program and was willing to go to great lengths to get it.

Unfortunately his local Medicaid office, which opened at 8AM, only granted interviews to the first 30 people to arrive each day. By 7:45, all those spots were already filled by people waiting in line.

Because of his Parkinson's, Mr. C no longer had a valid driver's license and relied on public transportation to get around and, even though he had caught the first bus of the day, Mr. C always arrived too late to get an interview.

Conclusion

Paperwork should be understood for a lot more than not just a hassle or an economic loss. Paperwork should also be recognized as an often insurmountable barrier to needed health care and other human services.

A straight-forward prescription drug benefit for people is what any competent doctor would order, and what we believe any Congressional committee seeking a streamlined and fair system of government should support. To ease the hardship on 43 million Americans with Medicare we ask that you consider:

1. **Enacting a Medicare drug benefit that operates like Medicare Part B.** A Medicare drug benefit would let people use their Medicare card at any pharmacy, anywhere in the country. A Medicare drug benefit would allow the government to negotiate drug prices, leveraging Medicare's 43 million members to lower costs for themselves and the American taxpayer. A Medicare drug benefit would guarantee people with Medicare can get the drugs they need.
2. **Automatically enrolling eligible people with Medicare in the Extra Help Program.** To do so, you can rely on the same federal financial data currently used to verify the application individuals submit and utilize the same opt-out enrollment process that has led to 96 percent enrollment in Medicare Part B.